

## Data/Research Requests – Frequently Asked Questions

### What data is publicly available?

Please visit the “Statistics” section of our webpage to view donation and transplantation data that Trillium Gift of Life Network (TGLN) shares publicly: <https://www.giftoflife.on.ca/en/publicreporting.htm>

If you are a member of the public looking for information not found on our website, see the instructions for how to make an [Access to Information](#) request.

If you are a journalist looking for information not found on our website, please contact Margaret Barng, *Manager, Public Education and Marketing* at 416-619-2389 or [MBarng@giftoflife.on.ca](mailto:MBarng@giftoflife.on.ca).

### What additional data is commonly requested and readily available from TGLN?

#### Donation Data –

- Referrals
- Number of Donors per Donor Type: Neurological Determination of Death (NDD) and Donation after Circulatory Death (DCD)
- Consented Not Recovered
- Recovered Not Transplanted
- Number of Approaches, Consents, and Declines
- Organs Transplanted per Donor
- Type and number of Organ transplanted per time period by hospital

#### Transplantation Data –

- Transplants by Donor Type
- Wait List Activity: Number of Additions; Removals; Reason for Removal
- Average Wait Time per Organ Transplant

### Does TGLN have the authority to support and collect information for research related to organ and tissue donation?

**Yes**, the *Trillium Gift of Life Network Act* (the “Act”) allows TGLN to plan, promote, co-ordinate and support activities relating to the donation of tissue<sup>1</sup> for transplant and activities relating to education or research in connection with the donation of tissue and to collect, analyse and publish information relating to the donation and use of tissue.

### What elements of research does TGLN’s “Consent to Donate Organs and/or Tissue” apply to?

Under the Act, the patient’s substitute decision maker may provide consent for donated tissue to be used for the purposes of medical education and/or research. A list of applicable tissue is specified on the Consent to Donate Organs and/or Tissue form; tissue not listed can be written in. Should tissue be unsuitable for transplantation, consent for research is indicated by checking the “Scientific Research” option.

Because “blood” is exempt from the Act, TGLN has included a section specific to the collection of blood or other body fluid for research purposes on its Consent to Donate Organs and/or Tissue form.

A second consent form specific to the research initiative at hand may be required by a Research Ethics Board (REB), or if TGLN identifies the research as outside the scope of its Consent to Donate Organs and/or Tissue form.

<sup>1</sup> “tissue” means a part of a living or dead human body and includes an organ but, does not include bone marrow, spermatozoa, an ovum, an embryo, a foetus, blood or blood constituents; (“tissu”)

**Will TGLN obtain consent for research related to donation or transplantation when donated tissue is involved?**

Yes. When TGLN’s trained Organ and Tissue Donation Coordinator or Family Discussion Coordinator approaches the patient’s substitute decision maker for consent to donation for the purposes of transplantation, they will also obtain consent for research. TGLN or the REB may require an information sheet outlining the specifics of the study be provided, to ensure the TGLN coordinator is able to answer any questions that may arise with regard to the research initiative.

However, TGLN reserves the right to defer obtaining consent for research to the Principal Investigator if the research is considered beyond the scope of the TGLN coordinator’s responsibility. In these situations, the TGLN coordinator will ask the patient’s substitute decision maker for permission to provide their contact information to the Principal Investigator.

**Does TGLN facilitate consent for donation of tissue when the research is not related to donation or transplantation?**

**No.** Research Requests must result in the potential to increase registration and consent rates; increase organ and tissue donor numbers; increase the number of transplants; improve transplant outcomes; or ensure data quality/validation that supports donation and/or transplant clinical practice.

**Is a Data Sharing Agreement required between hospitals, TGLN and or the Principal Investigator(s)?**

TGLN does not require a Data Sharing Agreement with designated facilities<sup>2</sup>, including hospitals.

TGLN has the authority to disclose data for the purposes of research to a designated facility,

where measures are in place to appropriately safeguard and protect data, in accordance with applicable legislation. In the instances where the data is provided to a third party that is not considered a designated facility under the Act, an agreement between TGLN and the Principal Investigator is obtained. An agreement is not required for data that is anonymized, aggregate and publicly available.

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<sup>2</sup>“designated facility” means a hospital, health facility or other entity designated as a member of a prescribed class of facilities under section 8.